



INTELLECTUAL & DEVELOPMENTAL DISABILITIES

An Introduction to
Community Supports
in Kansas

101



MEET EMILY

Today, Emily is not afraid to stand up for her own beliefs, even if it means starting a petition or a list of reasons to support what she is advocating for, but years ago, her life was very different.

Emily was born weighing one pound, six ounces, which was followed by severe complications after an extended stay in the hospital. As a young adult, Emily faced anxiety and depression, causing her to struggle to maintain a healthy lifestyle. But in 2009, Emily began services at Big Lakes, moved to a group home, graduated from high school in 2011, and began working full-time as a janitor in the Big Lakes workshop.

Now, Emily is trained to provide peer support to others in need, serves on the Council of Community Members Board, was chosen for the Big Lakes Behavior Management Committee, and participated in the U.S. Special Olympics games in Seattle.

Emily's hard work has paid off, and her independence continues to shine as she accomplishes her goals and overcomes any obstacle in her path!

WHAT IS I/DD?

The Developmental Disabilities Assistance and Bill of Rights Act¹ defines an intellectual/developmental disability (I/DD) as a severe chronic disability which...

- Originated at birth or manifests before the age of 22
- Is expected to continue indefinitely.
- Substantially restricts the individual's functioning in several major life activities.
- Is attributable to mental or physical impairment

MORE SPECIFICALLY...

An intellectual/developmental disability is a severe, chronic disability which results in substantial functional limitations in three or more of the following areas of major life activity:

- Self-care
- Expressive language
- Learning
- Mobility
- Capacity for independent living
- Capacity for self-sufficiency

With community services, people with I/DD are often able to be more active, productive, and independent, which benefits their communities as well!

EXAMPLES OF I/DD:

- Autism
- Brain Injury
- Cerebral Palsy
- Down Syndrome
- Fetal Alcohol Syndrome
- Intellectual or cognitive deficits
- Spina Bifida

¹The Developmental Disabilities Assistance and Bill of Rights Act was last authorized by the U.S. Congress in 2000. This Act can be found in full here: <https://acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000>



MEET REYNA

Reyna, just over two years old now, has been receiving Rainbows services since she was born. Her family's first connection with Rainbows came through a doctor's referral, as Reyna was born with Down syndrome.

"It was painful to find out, and we didn't know what to do or expect," said Reyna's mother, Laura, about hearing the initial diagnosis. "We had no experience with others who had Down syndrome, and we often felt scared. I even cried about the difficulties in the beginning, just because of all the unknowns coming for my daughter."

Over the past two years, Reyna has received physical therapy, occupational therapy, and speech therapy all through Rainbows. Reyna reached a huge milestone this past January and her PT sessions have since stopped. Reyna no longer sees a PT regularly because she is now walking just like any other two-year-old!

Reyna is currently working on fine motor skills and utensil use with her occupational therapist and multiple language goals with her speech therapist. "When I see Reyna, we work on play skills using books and puzzles, practice sign language, and work towards other important speech objectives," said Katie, Reyna's Speech Language Pathologist. "Pretending and imitation is important at her age so we spend a lot of time on that as well. Reyna's pre-verbal skills and foundational problem-solving skills have improved so much! This is in large part because her family is so great at working with Reyna daily, implementing tools or activities we have given them."

Reyna's family is grateful for Rainbows and what these services have meant to them. "I now tell other families with children about Rainbows," said Laura. "I tell them about these special services and how they have stepped into our lives and made a difference."

Though they had many concerns when Reyna was born, her family can't imagine life without her now. "We don't worry about her as much these days, and treat her no different than anyone else," said Laura. "She is just as loved and perfect as our other three children."

HISTORY OF KANSAS I/DD SERVICES

In the not-so-distant past, parents of infants with I/DD were often told by their physicians to give their children up for institutionalization. Generations of families were split apart by these choices.

Beginning in the 1950's, parents of children with I/DD urged their communities to develop local resources and supports for their sons and daughters. Communities responded by developing community-based nonprofit organizations and with time, children with I/DD were integrated into public education. State leaders helped implement these changes by providing increased levels of funding for these community efforts.



Institutions were a Victorian-era solution for the care of persons with disabilities. Pictured above is the Topeka State Hospital.

The 1970's saw passage of key Federal acts promoting the rights of persons with disabilities, as well as an increasing realization that institutional models were outdated and out of alignment with emerging societal values of diversity, integration and inclusion.

In 1995, the passage of the Kansas DD Reform Act (DDRA) sought to integrate Kansans with I/DD as fully participating citizens in their community. The Act contains four guiding principles for supporting persons with I/DD, engaging them in work and activities that maximize their abilities:

- Independence
- Integration
- Inclusion
- Productivity



Students with I/DD in an integrated school setting.

As a result of the combined efforts of the State and communities during the past four decades, a vibrant network of support has been developed to aid persons with intellectual and developmental disabilities to live independent and productive lives in Kansas communities of their choice.



Anisa Jalil and Elander Standifer share a laugh with Kelly Puttroff (center), an individual served at Starkey, during lunch.

INTERACTING WITH PEOPLE WITH I/DD

The Illinois Department of Human Services provides some great advice when it comes to interacting with persons with I/DD:

“When you interact with people with disabilities, focus on their abilities, not their disabilities. People with disabilities are unique individuals who have a wealth of knowledge, skills, talents, interests, and experiences that add tremendous diversity, resourcefulness, and creative energy to our society.

Remember, people with disabilities may do things in different ways than people without disabilities, but they can achieve the same outcomes.”

WHAT IS "PERSON FIRST" LANGUAGE?

Instead of saying "disabled person", we say "person with a disability". This emphasizes that they are "a person first" who just happens to have a disability.

KANSAS I/DD SERVICES TODAY:

Kansans with intellectual/developmental disabilities receive supports from a statewide network of community providers of long-term, non-medical services. More than 9,000 Kansas children and adults are currently served by the I/DD service system. Services range from early screening and remedial therapy for infants and toddlers to residential support, day activities, and employment services for adults. Kansas has a strong I/DD network with a positive national reputation.



KANSAN WITH I/DD

KANCARE

Kansas utilizes managed care model known as KanCare for all Medicaid funds. Individuals must enroll as a member with one of three available managed care organizations: Aetna, Sunflower Health Plan, or United Healthcare.



CDDO: COMMUNITY DEVELOPMENTAL DISABILITY ORGANIZATION

There are 27 CDDOs throughout the state that act as gatekeepers to the Kansas DD System. CDDOs are nonprofit or county-operated organizations that determine eligibility, assess the individual's needs and inform the individual of service options. CDDOs are contracted by the State with oversight from the Kansas Department on Aging and Disability Services.



IS FUNDING AVAILABLE?

Approximately 95% of state funding of I/DD services comes from the Medicaid program, of which 45% of the funds are State dollars and 55% are Federal. On average, the current program costs about \$45,000 per individual per year. This is less than 1/4 of the cost incurred by serving an individual in an institutional setting.

YES



CSP: COMMUNITY SERVICE PROVIDER
Community Service Providers are community-based organizations that provide long-term support to enable persons with I/DD to live independent, productive and fulfilling lives. CSPs can vary in size; a small organization may serve 1-3 individuals, whereas a large organization may serve 400 or more. CSPs offer a variety of services to enable persons with I/DD to achieve life goals. Examples of services include: Case Management, In-home respite, Community Employment, Residential support, Health services, Retirement program, Day program.

NO



I/DD WAITING LIST
The waiting list is approximately eight years long and currently has nearly 3,900 Kansans with I/DD in need of services.



BUILDING A FUTURE TOGETHER

What does the future hold for Kansans with intellectual and developmental disabilities? Many challenges lie ahead for Kansans with I/DD including the elimination of waiting lists for services, a direct-care workforce crisis spurred by decades of chronic under-funding and sweeping changes to Kansas Medicaid programs through managed care.

While the future is uncertain and challenges exist, we are hopeful that we can continue to work with you, our elected leaders to pursue the best possible outcomes for Kansans with I/DD and the organizations that serve them.



This information was brought to you by InterHab, the state's oldest and largest association of I/DD service providers. With more than 40 members from communities across the state, we are your experts to rely on for information about the Kansas I/DD system. We invite you to get to know Kansans with intellectual and developmental disabilities and the organizations that serve them. If you would like to get in touch with your local InterHab members, please contact us today and we will put you in touch with organizations from your area!

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